



LIFESPARK

igniting victories for parkinsons

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Past or Present?

Rabbi Yitzchok Aryeh Epstein

In the ברכה after we finish reading the מגילה, we say את ריבנו והדן את דיננו והנוקם את נקמתנו הרב. We are praising Hashem for fighting our fights & taking revenge for us. Note the tense is present. He is still currently doing this for us on a daily basis. Yet in the חנוכה of הנסים על, we say ריבם דנת את דינם נקמת את נקמתם רבת את, the same thought just in the past tense. Why is the נוסח different for פורים than by חנוכה?

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Parkinson's and Your Children/ Teenagers

Parkinson's disease (PD) is a family affair: everyone in your family is affected. As a parent of a young child or teen, it is important to consider how PD might affect your children and what can be done to continue to live a full family life with PD. A parent's illness can present challenges for a family, but it can also provide opportunities for children to grow in ways they may never have

experienced without the health issue. The good news is that children often adjust well to a loved one's diagnosis of PD. With support, they not only adjust but also thrive and can become more self-sufficient, confident and independent.

As symptoms of PD vary for each person, so do the emotions of each child. Common emotions include:

- ✂ Shame or self-consciousness about the unusual presentation of PD, especially as a result of reactions by friends or strangers.
- ✂ Anxiety about the stress in the parent's marital relationship caused by PD. Children may sense tension between parents due to the diagnosis and/or the symptoms of PD.
- ✂ Sadness, fear, anger and grief regarding the changes and

losses of parent experiences or limitations of future experiences.

✂ Loneliness as the healthy parent is more focused on and spends more time with the person with Parkinson's.

✂ Worry about their risk of developing PD themselves; worry that parents feel guilty about the impact of PD on the family, financial worry if family income has changed due to working less or disability pension; worry about the impact of PD on their own future aspirations and decisions.

✂ Feeling overwhelmed by caregiving responsibilities.

✂ Frustration with activity restrictions including finding it harder to socialize as they do not want to bring friends home or feel bad about going out.

Research Based Recommendations

Research into the impact of PD on children is still new, but most children report that they have someone to talk to about their feelings. We have also learned that a child's outlook was strongly tied to that of his/her parent—if a parent was hopeful, often the child was too.

Share the diagnosis

Your instinct may be to hold back sharing information about PD as you fear it may create worry for your children. However, regardless of the age of your children, consider telling them you have Parkinson's. Many children who have a parent with PD said that they did not have enough information and that a better understanding of PD would help them feel more secure. Children often

imagine much worse things than the truth. Explain Parkinson's to them, as well as your best understanding of what might happen. Let children know that PD is not fatal, that they are not responsible for it and it is not contagious. Remember to use age-appropriate language. A better understanding of the condition can actually lead to less distress and allow them to feel more secure.

This is especially important with adolescents, who have access to a lot of information via the internet. This can be constructive if what they find helps them cope, but it can be devastating if the information is misunderstood. Consider asking your teen what they know about PD and where they found their information. Ask if they plan to get more information, and from where. You might want to go online together to sites that you know are reliable, like Parkinson.org, rather than simply googling "Parkinson's."

Privacy for your child/teen and for you. Your children may not want to talk to you about PD. This is okay, but it is important that they have someone to talk to, whether it is another relative, friend, parent of a friend, teacher, coach, clergy or other person in their lives. You may not want your diagnosis or disease process to be shared with the entire community. To meet your needs for privacy and your child/teenager's need for support, discuss what information he/she can share and with whom.



What You Can Do to Help Children Adjust to PD

Share with your children's school about changes in your home if at all possible. The staff at the school, along with sports coaches or leaders of other extracurricular activities, can be your allies in watching over your children's emotional health and looking out for signs of distress. Sharing accurate PD information with the other adults in their lives will help ensure that your attitude and philosophies are always communicated in a similar way.

Establish family meetings to create opportunities to regularly address issues and worries, along with what is working well. You may use one of the books about Parkinson's written for children as a jumping off point for the discussion. Below you'll find a list of a few of these books for reference. As PD is a progressive condition and will change over time, new questions may come up and need to be addressed. Plan a fun ac-

tivity following a “PD” talk.

Maintain family life, while remaining flexible with the changes that occur. Encourage and reassure your kids to continue their involvement in favorite activities, interests and hobbies. They should have fun and live their “normal” lives as much as possible. This is important for their overall wellbeing.

Help your children find peer support. They are not the only ones with parents with PD. If you are in a Young Onset PD support group, ask other members if they have children and if they might want to arrange an activity where children could meet or connect anonymously online. You could also ask members of your health care team (neurologist, social worker, nurse) to link your children with others in a similar situation.

Bring children to a neurology appointment so they can learn about PD. If they are interested, you can talk more about research into new treatments and with specialists who are available to help.

Empower children by helping them organize a PD fundraiser or raise PD awareness. It is something they can do to help.

Demonstrate a positive attitude. Children learn a lot about coping from their parents. Model healthy coping by sharing your honest feelings appropriately as well as using strategies to cope like exercise and connecting with friends. Instill hope by reminding them that there are teams of specialists and researchers working on PD treatments and symptom management.

Final Thoughts

It is vital for children to continue to see their parent with PD as a parent first and foremost, with the same expectations & approaches



If a parent was hopeful, often the child was too.

to parenting, enforcing the same discipline and boundaries. Stability and consistency will create a sense of security for children.

Children, like adults, may have to grieve changes in their life and ongoing losses. They should be given permission to do so. Your children might have to work through their sadness before they can adjust to a new reality.

You are the expert on your children. If you sense that something is wrong, you are probably right. Keep in mind that childhood and teenage years are times of social and emotional development and stressors, and remember their distress may have nothing to do with PD. Consider counseling to meet their needs.

Parkinson's Books for Kids

The following books were written to facilitate discussion with

children about Parkinson's disease. The books offer age-appropriate information about PD and perspectives to help children and teens better understand important issues in the PD world. This is not a comprehensive list of available titles, but it's a great place to start. All of the books below are available on Amazon.com and other online retailers.

- I'll Hold Your Hand, So You Won't Fall: A Child's Guide to Parkinson's Disease** by Rasheda Ali, with a foreword by Muhammad Ali
- Carina and Her Care Partner Gramma** by Kirk Hall
- Carson and His Shaky Paws Grampa** by Kirk Hall
- My GrandPa's Shaky Hands** by Dr. Soania Mathur
- Parkinson's in the Park: For Children of Parents with Parkinson's** by Jessica Christie
- Shaky Hands: A Kid's Guide to Parkinson's Disease** by Dr. Soania Mathur
- The Tale of a Parkie Princess: A Chronic Illness Described in a Fairy Tale** by Annie Konopka



פורים

Part of a Whole

As פורים approaches, let us consider a lesson we are taught along the miraculous journey of this יום טוב.

When המן legislates his original intention to destroy the Jewish people, he writes something peculiar. He writes: להשמיד להרוג ולאבד את כל היהודים מנער ועד זקן טף ונשים ביום אחד. He insisted on annihilating everyone in **one day!** What was the significance of one day? Would it have been much different if the destruction would have occurred over two or three days?

The seforim explain that Haman knew the secret of ציבור, the tremendous potency and power of the wholesome entity of כלל ישראל. Aside from the reality of the many individual נשמות, there is something unique about the ציבור of כלל ישראל as a whole.

The גמרא tells us, that although regarding the קרבן of an individual, if the owner

were to die, the קרבן cannot be brought in their name, for a deceased person cannot attain the כפרה of a קרבן, nonetheless, a קרבן ציבור that was consecrated for the whole of כלל ישראל, even if the whole generation were to pass on, the קרבן may be brought, because: ציבור לא מתה! The entity and reality of a ציבור, the wholesome group of ישראל כלל, never passes on. The reality of the ציבור lives forever!

Haman knew of this secret. Therefore, he desired to destroy the entity of the nation in **one day**, taking down ישראל כלל as **a whole**, as a complete unit. He figured that in this way he would not only be erasing the individuals of the Jewish people, but even the ציבור, guaranteeing to erase our existence forever, ושלום חס. Haman failed, for this entity called ציבור is made of spiritual substance, the eternal stuff that cannot be destroyed through any physical force or means.

While this lesson is always paramount, and is indeed the secret of our everlasting survival, however, it is even more relevant now, in our troubled times when the ugly hatred of עשו and עמלק once again rears its noxious head. We must integrate this lesson deep into our souls, connecting to the infinite power of ציבור, therein finding life and vitality.

We here at the LifeSpark family appreciate this concept enormously. Aside from assisting individuals and families, we strive to create a sense of family, of ציבור. A place wherein the individual can feel part of something greater than themselves; a part of a whole, an extension of the eternal life-force of כלל ישראל, plugging in to the life generating quality of ציבור, alive, always and forever.

Ah Freilichen Purim,
Rabbi Tzvi Feuer
& the LifeSpark Family

THE “P” WORD

A few thoughts on Parkinson & Purim



Recipe Corner:

HAMENTASCHEN

3 eggs
 1 cup sugar
 2 teaspoons vanilla sugar
 3/4 cup oil
 1/3 cup water
 2 teaspoons Vanilla Extract
 1/8 teaspoon Almond Extract (optional)
 3 teaspoons Baking Powder
 5 1/2 – 6 cups flour
 your choice of filling

Beat eggs and sugar until creamy. Add oil and beat. Add water and extracts. Add baking powder. Gradually add flour until the dough comes together and becomes a good dough consistency.

Cover and refrigerate for an hour.

Roll out dough to a quarter inch thickness, and using a cup or round cookie cutter, cut out round circles.

Fill with favorite filling. Pinch each circle into a hamantashen shape.

Bake at 350 degrees for approximately 17 minutes (until bottom is golden).

Let's start at the very beginning (a very good place to start). Both Parkinson and Purim begin with the letter “P” and, incredibly enough, in both words, “R” is the third letter. Pretty (there we go with that P-R again...) cool, no? (and yes, I mean no. Hmm...I am definitely getting confused. Hey, that's also part of Purim).

Is there such a thing as an English gematria?

On Purim, life becomes very chaotic. Sometimes we become a bit wobbly on our feet. And lose our balance. And look like we're drunk. And we might even shake. And even feel that our life is spinning. Just like in Parkinson.

On Purim, we try (or at least some of us try, especially the **ezer k'negdo** types) to be in control. To make sure that we get up early so that we can hear the Megillah with plenty of time to send out the **shalach manos** to the right people at the right time, and make sure everything is organized for the **seuda**, which we scheduled to begin at 3:47 sharp! But then everything becomes **n'hafoch hu**. The Megillah reading starts half an hour late, and the Haman groggers are far from groggy. The shalach manos get all mixed up (you mean you accidentally gave the package with the expensive champagne and set of crystal dishes to the FILL IN THE BLANK instead of the FILL IN THE BLANK?) And as for

the **seuda**, well, by the time it begins, almost two hours late, everyone is either **shikkur** or on a sugar high. And although no one's hungry for that delicious brisket, everyone still has room for that gooey chocolate mousse (I really shouldn't, but I will).

With Parkinson, we think we know what we're doing, and we try to stay in control. But then life sends us another curve ball, and everything becomes **n'hafoch hu**. And just like on Purim, when things don't go as we thought it should, we take a deep breath and remind ourselves, “This is what Hashem wants. Nothing is going as I planned, but I'm not the Planner. And since He planned it this way, I'll find new ways to cope and even discover the presents hidden in the challenges (hey, with all those leftovers, I don't have to cook until after Pesach!).”

After all, that's what Purim is all about – realizing that Hashem is pulling all the strings, that everything He does, even when it appears to be terrible, is really all part of a Divine Plan, and for our ultimate salvation. It's about accepting Hashem as our King, and turning (and returning) to Him. And then dancing and singing, and truly rejoicing, because we understand that nothing in this world is as it appears.

And that really is funny.

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PUZZLE TIME

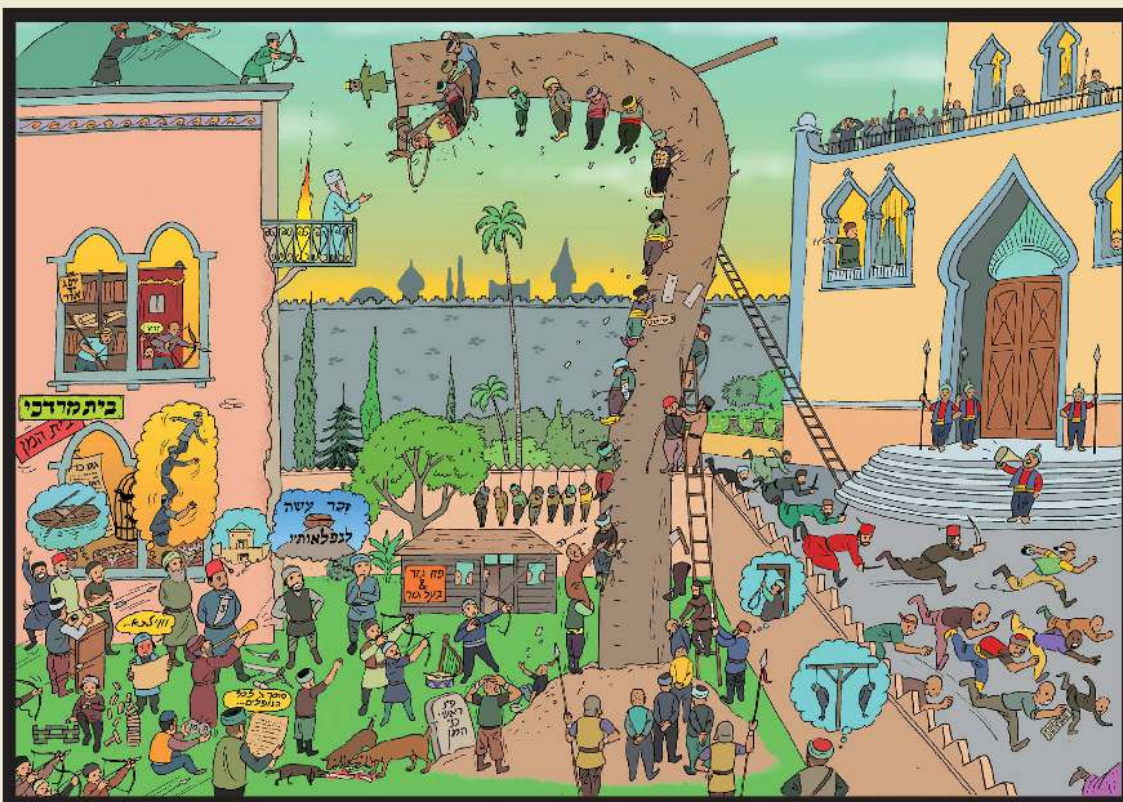
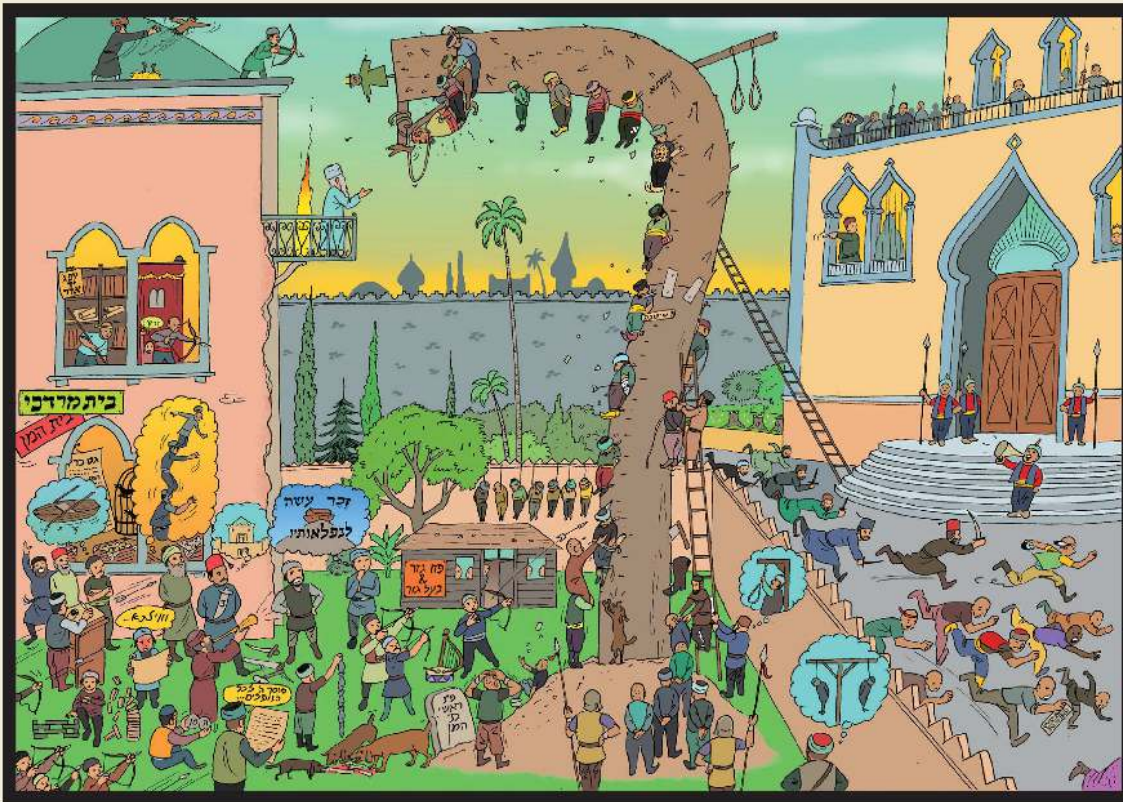
SPOT THE DIFFERENCES IN THESE TWO PURIM DRAWINGS

PAST OR PRESENT?

CONTINUED FROM COVER

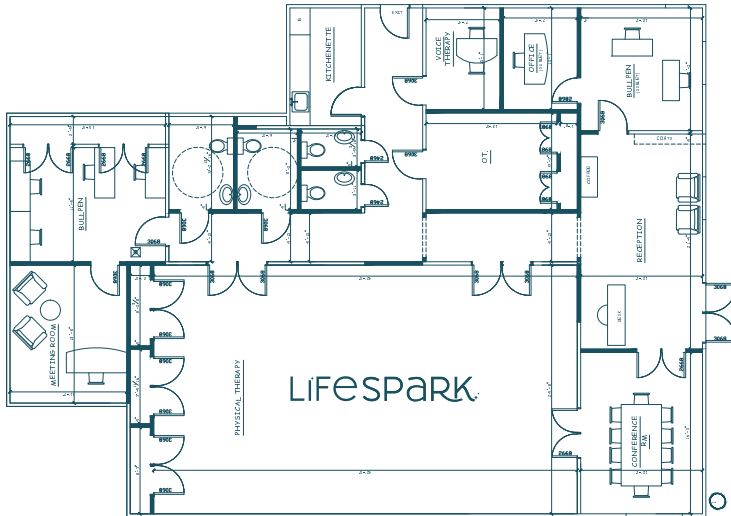
The answer is, the **נס** of **התוכה** was a **נס גלוי**, an open miracle that was blatant for all to see! It was **בד מפתים** A few **מכבי** Yidden destroyed the entire Greek-Syrian army consisting of hundreds of thousands of soldiers & elephants! Such **נסים** don't happen anymore until the time of **משיח**, when once again the greatness of Hashem will be displayed **בימינו**. **במהרה**. Thus, we praise Hashem in the past tense.

But the **נס** of **פורים** was a **נס** of **הסתר**. It was veiled! No one dreamed that the demise of **ושתי**, the appointment of **אסתר**, the parties of **אסתר**, etc. were all a lead up to the **נס** of **פורים**. **נסים** of this 'hidden' category, happen every day! **יעל נסיד שבכל יום עמנו**! It's present! Therefore, when we make the **ברכה** on **פורים** and we praise Hashem for the **נס** of **פורים** which was a **נס** of **הסתר**, we include in the **ברכה** all the **נסים** that Hashem is currently doing for us, every single day! Thus, we use the present tense! Ah Freilichen Purim!



Center Updates:

The construction of our Lakewood Centre is underway. We look forward to servicing you in person shortly after Pesach.



LIFESPARK
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Stay Tuned!

Look out for
upcoming information
about our

BROOKLYN WOMEN'S EVENT